PASSAGES

Bridging Pediatric and Adult Health Care for Patients with Red Cell and Other Rare Blood Disorders

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OBJECTIVES

- Define what a medical transition is.
- Understand the transition process.
- Know the difference between a successful and unsuccessful transition.
- Learn how to support a patient and their family through the transition process.

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HEALTHCARE TRANSITION

"Purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered care to adult-oriented healthcare systems" (Society of Adolescent Medicine)

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TRANSITION STATEMENTS OR POLICY

- American Society of Pediatric Hematology Oncology
- Association of Pediatric Hematology Oncology Nurses
- American Society of Hematology
- American Academy of Pediatrics
- American Academy of Family Physicians
- American College of Physicians
- Society for Adolescent Medicine

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BARRIERS TO TRANSITION

- Insurance (Medi-Cal)
- Lack of knowledgeable adult providers
- Lack of interest in taking care of complex young adults with chronic childhood illness
- Lack of patient and family education
- Unrealistic expectations of adult care
- Navigating the complexity of adult healthcare
- What happens when a patient loses their CCS
- Demographics
- Fear of suboptimal care and unknown
- Poor healthcare literacy

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Cost of Suboptimal Care

- Cost of suboptimal care is high
  - Increase in ED utilization and hospitalization
  - Increase in re-hospitalization
- Decrease in life span
  - Lack of follow up for preventable complications

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Preparation
Self-A
ntability
Growth
Empowerment
Success

PASSAGES

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PREPARATION
- Education
- Transition Clinic

SELF-ADVOCACY
- Learning how to problem solve without medical team jumping in to help

SUPPORT
- Support through the process
- Availability of experts

LIFE SKILLS
- Name it and Explain it
- Ordering Refills
- Scheduling appts

ACCOUNTABILITY
- Responsibility of medical care, making appointments, self care

GROWTH
Learning to care for own medical needs

EMPOWERMENT
- Self-efficacy
- Positive self image

SUCCESS
- Connection to adult care

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•Why use the word bridge? Crossing a bridge can be frightening if you don't know what is on the other side.




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I DON'T WANT TO GO!
Transition Before PASSAGES

Angela's Story
- 21 year old with rare blood disorder and transfusion dependent
- Aged out of CHLA inpatient care but remained connected to outpatient care
- Intermittently compliant with transfusions and outpatient care
- Numerous psychosocial stressors; major stressor was unexpected death of primary support person
- Expressed ongoing anxiety and resistance regarding transitioning to adult care

Unsuccessful Transition
- Patient given contact information for adult hematologist and assistance in scheduling appointments
- Several missed appointments, but eventually connected
- After 21, patient had increased need for hospitalizations
- Lacked trust in adult provider and hospital → sought care at CHLA Emergency Department which was familiar to her
  - **25 visits to CHLA Emergency Department during18-month period following 21st birthday**
- Attempts to follow-up with patient to were unsuccessful

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The Two-Pronged Approach

1. **TRANSITION PREPARATION**
   - Transition Clinic every other month
     - Multidisciplinary Approach for Patients 18yo to 21yo
     - Medical component
       - General education regarding disease processes
       - Specific education regarding individual disease process
       - Identify gaps in knowledge for individualized education
     - Social Work component
       - Assess and support coping with transition process with parent and patient
       - Education regarding navigating the insurance landscape
       - Education regarding legal changes and their impact on care
     - Nurse Navigator component
       - Education regarding differences in adult healthcare
       - Connection to adult providers

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2. **DEVELOPING THE PROVIDER NETWORK**
   - Multidisciplinary Approach
     - Medical Component
       - Meet new adult providers
       - Provide education to adult providers as needed
     - Nurse Navigator Component
       - Meet new adult providers
       - Establish method of bi-directional communication
       - Provide support to adult providers
       - Establish trusting relationship with adult providers
     - Social Work Component
       - Meet office staff of adult providers
       - Establish method of communication with office staff
       - Establish relationship with office staff

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We Treat Kids Better
ANTELOPE VALLEY
SANTA CLARITA VALLEY
SAN FERNANDO VALLEY
WEST LOS ANGELES
SAN GABRIEL VALLEY
LOS ANGELES CENTRAL
SOUTH BAY
Pacific Ocean
This map shows the locations and distance from CHLA of the adult providers in our network.
★ Loma Linda/San Bernardino
★ Antelope Valley/Lancaster
★ Monterrey Park
★ Pasadena
★ Downtown Los Angeles
★ West Los Angeles
★ Santa Monica
★ Torrance/South Bay/Long Beach
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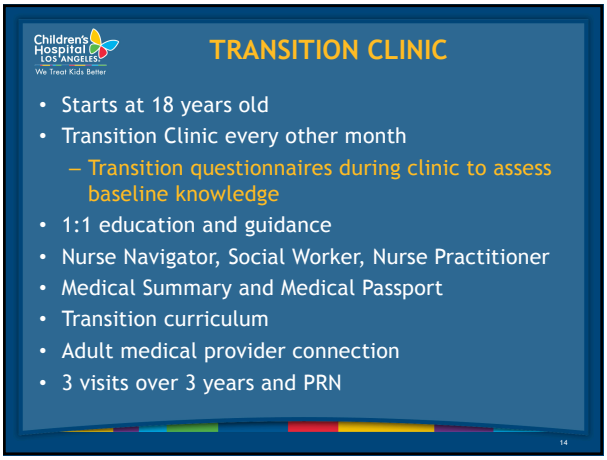
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TRANSITION CLINIC
• Starts at 18 years old
• Transition Clinic every other month
– Transition questionnaires during clinic to assess baseline knowledge
• 1:1 education and guidance
• Nurse Navigator, Social Worker, Nurse Practitioner
• Medical Summary and Medical Passport
• Transition curriculum
• Adult medical provider connection
• 3 visits over 3 years and PRN
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INDIVIDUAL NEEDS
• Tailor patient education to individual needs
• Transition questionnaire
– Based on patients' initial assessment, identify strengths and weaknesses and tailor transition education and support
• Neuro-psych screening
– Results can dictate level of support needed
– Informative to accepting adult providers regarding patient needs
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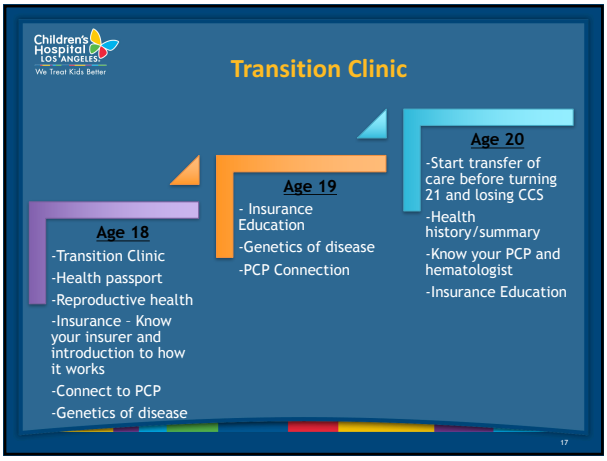
INTEGRATING TRANSITION INTO CLINICAL PRACTICE
Tiered Approach to Transition
Age 12-13
-Vitals with MA on own
-Know medications, amounts and reason for taking
Age 14-15
-One-on-one with provider for part of visit
-Be able to Name and Explain diagnosis and medications
-Know baseline hemoglobin
Age 16-17
-Patient will order his/her own meds
-Patient will know how to read a prescription bottle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Transition Clinic
Age 18
-Transition Clinic
-Health passport
-Reproductive health
-Insurance - Know your insurer and introduction to how it works
-Connect to PCP
-Genetics of disease
Age 19
- Insurance Education
-Genetics of disease
-PCP Connection
Age 20
-Start transfer of care before turning 21 and losing CCS
-Health history/summary
-Know your PCP and hematologist
-Insurance Education
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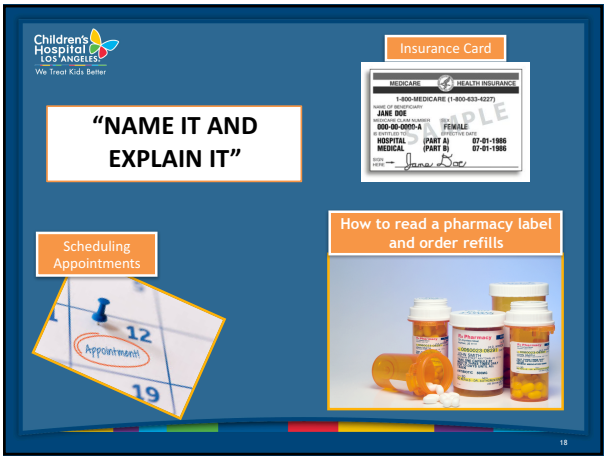
Children's Hospital LOS ANGELES
We Treat Kids Better
"NAME IT AND EXPLAIN IT"
Insurance Card
Scheduling Appointments
How to read a pharmacy label and order refills
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IT'S ALL ABOUT INSURANCE

COVERED CALIFORNIA

Anthem Blue Cross · Molina Healthcare · Kaiser Permanente · blue of california · Health Net · Valley Health Plan · LA Care Health Plan · Western Health Advantage · SHARP · CCHP · oscar · Medi-Cal

Offered for Small Businesses

Offered for Individual and Family

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Teaching a Patient to Advocate

Mary's Story

- 22 yo women with beta thalassemia major
- Transfused every 3 weeks
- Suddenly lost access to CHLA for care
- Worked with her PCP for 1 more tx at CHLA
- Connected her to adult hematology provider in our network
- Assisted with changing her insurance

Teaching Her to Advocate

- New PCP she was assigned to doesn't take new MediCal pts
- 3 way call with insurance to change PCP to one who will take new pts
- Received referral to adult hematologist but needed guidance on scheduling appts.
- Guided her through navigating and negotiating with her new insurance for referral for tx
- Guided her through working with new adult hematologist in how to advocate for her care

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FUTURE GOALS

- Improve insurance access strategies to expand medical care provided
- Strengthen relationships with current adult provider partners and expand outreach to additional hematology and PCP providers
  - Strengthen partnerships with community groups
- Standardize the transition process and integrate into medical care
- Disseminate information regarding programmatic success -publish
- Integrating FNP into medical care, creating a young adult clinic from 18-21yo

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"PASSAGES" Putting It All Together

Sally's Story

- 20 year old patient with rare blood disorder
- Unrelenting issues of acute and chronic pain
- Receiving medical care from several specialty clinics at CHLA, who provided no guidance with transition other than a list of referrals
- Patient very dependent upon mother to take care of her medical needs

PASSAGES At Work

- Referred to Transition Clinic
- Assisted with insurance change to access appropriate adult providers
- Educated on navigation of adult health care system
  - Attended appointments independent of parent
  - Ordered her medications
  - Improved comprehension of her diagnosis
- Connected to Nurse Navigator
  - **Collaborated with new PCP to connect her to case management, adult hematologist and subspecialists in her medical group**
  - **Had 1st appointment with adult provider**

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Lessons Learned

- Not one size fits all
  - PCP only
  - PCP and Hematologist
- Transition is a process
- Sometimes your providers are not ready to let go
- Realistic expectations
- Transition must start early!!!!!!

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TRANSITION TEAM

- **Dr. Jacquelyn Baskin - Medical Director
- **Dawn Canada, LCSW - Project Coordinator
- **Anne Nord, MSN, RN - Nurse Navigator
- **Michelle Lahat, LCSW-Social Worker
- **Tiffany Vu - Administrative Assistant
- Nathan Smith - Administrative Assistant
- Kelly Russell - Data Assistant/Community Outreach
- **Debbie Harris, PNP
- **Trish Peterson, PNP
- Sue Carson, PNP

**Core Transition team

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THANK YOU

- The Rauch Family Foundation
- The Italian Catholic Federation

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QUESTIONS?

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